

# Plan to Resume Data Collection of MLS-IPS Interviews Remotely

To date, there has been limited use of remote interviewing, using audiovisual programs to conduct interviews, of adults with Intellectual and Developmental Disabilities. The current COVID-19 pandemic that has resulted in shelter-in-place (SIP) orders for all parts of California and the lingering safety concerns related to the pandemic in resuming in-person interviews has highlighted the need for innovation in this area. This proposal outlines how to resume interviews for the Mover Longitudinal Study (MLS) with consideration for technological challenges and feasibility for study participants to participate in remote interviewing while maintaining the integrity of the data collected.

## Addressing MLS-IPS Interviews Missed Due to COVID-19 Shelter-In-Place Orders

In late March 2020, In-Person Survey (IPS) interviews being conducted for the MLS were suspended due to the statewide SIP order that went into effect to combat COVID-19. The level of restriction has fluctuated based on local factors since that time. A high level of caution remains in resuming typical activities of daily life, particularly for individuals who are medically fragile and older adults. By December 31, 2020 312 individuals will have missed their interview window for the MLS.

The design of the MLS allows for a four-week data collection period for interviews to take place that are scheduled based on the date the individual moved to their community placement. Due to the unparalleled circumstances, UC Davis recommends modifications to the study design to allow interviews that should have been conducted in November and December 2020 to be completed once interviews resume in January 2021. The goals of the modifications are: 1) maximize data collection from individuals whose data collection period was missed, 2) maintain the intent of the study to monitor individuals who moved from developmental centers (DC) at specific times points, 3) resume the standard data collection cycle in a remote format as quickly as possible. Adoptions of these modifications will result in 41 surveys being conducted outside of the data collection window, but close enough to it to maintain data integrity. To achieve these goals, UC Davis completed a review of available literature on remote interviewing techniques, and in partnership with State Council for Developmental Disabilities (SCDD) evaluated a variety of remote interviewing technology that best suits the needs and capabilities of the study participants and while maintaining research best practices.

## Lessons from Research Literature on Remote Interviewing

There is limited literature available on the topic of remote interviewing of individuals with I/DD. However, small scale studies of telemedicine approaches used to provide psychiatric services to individuals in remote locations have been conducted and offer promising results. An early study of 30 participants found that psychiatric assessment via telecommunication yielded nearly identical

psychiatric diagnoses as an in-person control group assessment.<sup>1</sup> Additional studies focusing specifically on remote psychiatric treatment of intellectually disabled participants found that 98% of participants using telemedicine reported the experience being better or the same as the in-person alternative.<sup>2</sup> Another positive finding indicated significant decreases in hospitalization rates, emergency room visits and annual support costs of individuals receiving telemedicine services.<sup>3</sup>

There are best practices that should be taken before, during, and after remote interviewing individuals with I/DD to insure the comfort of the individual being interviewed as well as maintain data collection standards. Research has shown that there is value in the interviewer and participant knowing information about one another before the study takes place (e.g., photo, concrete information)<sup>4</sup> and building rapport.<sup>5</sup> The interviewer should be approachable, and the dress code and titles of the interviewers should be predetermined and consistent throughout the study. Previous research has suggested it can be effective to introduce interviewers as their more formal title to staff/proxies and less formal title/name to participants to stress the importance of a personal approach.<sup>4</sup> Additionally, interviewers should consider dressing in casual style clothing rather than formalwear to establish more comfortability with the participants when appropriate.<sup>4</sup> At the beginning of the interview, participants should be made aware that the telecommunication platform is HIPPA compliant and asked to identify who else is on the call with them and what their role is in the patients' care.<sup>3</sup> Lastly, participants have indicated a motivation for continual participation in research when they receive results and/or feedback to participants after study information is available.<sup>4</sup>

SCDD, with consultation from UC Davis, has developed protocols staff will use to conduct remote interviews. The protocol is available separately from this proposal. While care has been taken in selecting the platform for remote interviewing and a review of available literature has been conducted to learn from previous uses of remote interviewing of adults with I/DD, it is important to note that unanticipated challenges in the use of technology and engaging individuals with limited verbal communication remain. Therefore, this data collection effort should be viewed as a pilot to learn and improve the use of remote interviewing techniques among adults with I/DD.

### About the MLS Population

The individuals who participate in the MLS are unique among the larger community of individuals with I/DD that DDS serves. To date, the majority of individuals who have participated in the MLS had very limited ability to communicate and were unable to complete the survey independently. There was only a small subset (less than 10%) of individuals who were able to complete the survey independently or with limited assistance. Due to the communication challenges of the movers, the MLS relies heavily on objective data gathered from proxy respondents on behalf of movers. Proxy respondents for the MLS

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<sup>1</sup> Ruskin, P.E., Reed, S., Kumar, R., Kling, M.A., Siegel, E., Rosem, M., Hauser, P. (1998). Reliability and acceptability of psychiatric diagnosis via telecommunication and audiovisual technology. *Psychiatric Services*, 49(8), 1086-1088. <https://doi.org/10.1176/ps.49.8.1086>

<sup>2</sup> Madhavan, G. (2019). Telepsychiatry in intellectual disability psychiatry: literature review. *BJPsych Bulletin*, 43, 167-173. doi:10.1192/bjb.2019.5

<sup>3</sup> Gentile, J.P., Cowen, A.E., Harper, B., Mast, R., Merrill, B. (2018). Reaching rural Ohio with intellectual disability psychiatry. *Journal of Telemedicine and Telecare*, 24(6), 434-439. doi: 10.1177/1357633X17706035

<sup>4</sup> Nicholson, L., Colyer, M., Cooper, S.-A. (2013). Recruitment to intellectual disability research: a qualitative study. *Journal of Intellectual Disability Research*, 57(7), 647-656. doi: 10.1111/j.1365-2788.2012.01573.x

<sup>5</sup> Corby, D., Taggart, L., Cousins, W. (2015). People with intellectual disability and human science research: a systematic review of phenomenological studies using interviews for data collection. *Research in Developmental Disabilities*, 47, 451-465. <http://dx.doi.org/10.1016/j.ridd.2015.09.001>

are most often staff but can also be family members, friends or conservators. As of December 31, 2019, almost all movers (98%) had a proxy respondent aid in the completion of the survey. Of those with proxy respondents, 81 percent of movers had a staff member from their home serve as their only proxy. Two percent of movers responded to the entire survey independently with no assistance from a proxy. Service Coordinators cannot act as proxy respondents due conflict of interest.

Due to the large majority of MLS participants participating in the study through a proxy respondent it makes for a good pilot for the use of remote interviewing focusing primarily of the technological challenges of conducting the interviews remotely. The fact that 81 percent of participants are responding by proxy who are staff at their home allows for interviews to be scheduled in a similar manner as they would be under normal conditions.

### *Recommendations based on survey time points*

The data collection windows for the MLS were designed to collect data as closely as possible to key dates after an individual moved to a community placement from a DC. Collection of data at these key time points allows for longitudinal tracking of the experience of individual movers over a period of time. The need for strict adherence to the four-week data collection window is most important for data collection periods that intend to capture the experience of individuals over short durations (e.g., the three-month and six-month time points), and less important for longer ranges of time (e.g., one-year post-move and beyond). Additionally, after four years of data collection, UC Davis has found minimal changes in responses between the three-month and the six-month time periods. Based on these tenets, we recommend the following:

#### *Three-Month Surveys*

The final three-month survey should have taken place in May 2020. The final individuals who moved from a DC to the community are now approaching their one-year mark of living in the community. Due to the length of time between when the three-month surveys should have taken place and the resumption of data collection, UC Davis does not recommend collecting any three-month survey missed. Instead, we recommend that SCDD collects the one-year surveys as they come up regardless the three-month time point being missed.

#### *Six-Month Surveys*

The six-month data collection time point has passed for all individuals active in the study. UC Davis does not recommend attempting to collect these surveys.

#### *Survey Collected at One-Year and Two-Year Time Points*

UC Davis recommends conducting all of the one-year and two-year post move surveys conducted in November and December 2020 as quickly as possible. However, priority for remote interviewing should be given to individuals who currently have their data collection windows open above those who missed their one-year or beyond survey points due to the SIP order.

Overall, it will be highly important for interviewers to accurately note interview and move dates so that UC Davis can account for changes to the MLS methodology in forthcoming analyses and reports.

### Survey Collection at Three-Year and Four-Year Time Points

The legislative mandate for the MLS was for each individual to be surveyed through two-years post move. Prior to the SIP order DDS had opted to extend surveying all individuals in the study annually until all had reached their two-year mark. However, due to the break in data collection and alterations to the study caused by the disruption in data collection, it was determined that data collection would end for each person after they are in the community for two years. Therefore, no surveys beyond the two-year time point should be conducted.